# My Baby, My Doctor & Me: Hearing from Parents about Early Infant Relationships and the Role of the Health Care System



Key Findings from a Focus Group with Latinx Mothers Across Oregon

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The Center's mission is to engage in equity-driven research, evaluation, and consultation to promote social justice for children, youth, families, and communities.



### **Background & Project Overview**

There is a growing national effort to encourage doctors, nurses and others to see the relationship between parents and their infants as central to children's health, and to support parents in developing these foundational early relationships (sometimes referred to as "early relational health" 1). As this work moves forward, it is important that it includes the voices of historically marginalized parents whose personal and cultural histories, experiences, and beliefs about parenting and the role of the health care system are included. This exploratory study aimed to center the voices of three very different communities to learn more about their beliefs about the nature of their earliest relationships with their young children and their perceptions of the potential role that health care providers could play in supporting them.

To do this we partnered with teams of "Parent Research Consultants" (PRCs) representing each of the three communities of interest: (1) African American mothers in urban Portland, Oregon; (2) Latinx mothers living in rural areas of Oregon; and (3) rural, geographically isolated White mothers in Southern Oregon. PRCs provided input to the research team about the design, measures, and data collection methods for the study, as well as on the interpretation and development of a set of research briefs, including this document. PRCs were provided with an honorarium for the time spent on the project. With

their guidance, we conducted three focus groups with members of each of these three diverse communities. Focus groups asked these parents to talk about:

- What early parent-infant relationships mean to them, and how positive relationships can be established;
- Where parents go for support for themselves and their babies;
- Their experiences with, and feelings about, the role of health care providers in supporting these earliest relationships;
- Their ideas and recommendations for how health care providers could approach these issues with families most effective;

This research brief summarizes findings from a focus group held in July 2020 with 11 Latina mothers to discuss their experiences as mothers of young babies and their relationships with medical providers. All of the mothers we spoke with had at least one child between the ages of 0-3, with children ranging in age between 7 months and 16 years. These mothers live in different parts of Oregon. Participants were very motivated to share their experiences and influence change, because they believe that medical providers do not understand Latino culture and that Latino families are not often asked to participate in these types of projects.

### **How Latina Mothers Describe a Healthy Baby**

Latina mothers described in great detail what they expect to see when their baby is healthy: A healthy baby is physically **active**, **sleeps well**, **eats well**, plays, and socializes with other children. These mothers clearly saw social-emotional development as a key part of their baby's well-being.

"Mi niña duerme toda la noche, desde que nació, es una bendición y siempre ha dormido toda la noche, y siempre se levanta contenta, siento que está feliz, que no está enferma... ¡Siempre está sonriendo! Solamente llora cuando tiene hambre o no puede dormirse. Si no estuviera contenta, estaría llorona, sentadita, sin querer hacer nada. Ella es muy

activa y así sé que está saludable" [My girl sleeps through the night, since she was born, it's a blessing and she has always slept through the night, and she always gets up content. I feel that she is happy, that she isn't sick. She's always smiling! She only cries when she is hungry or can't sleep. If she wasn't content, she would be crying, just sitting there, not wanting to do anything. She is very active and that's how I know she is healthy.]

"Cuando están muy felices, juegan, están contentos, comen bien, uno nota que están bien, conviven con los demás y son sociables." [When they are very happy, they play, they're

<sup>&</sup>lt;sup>1</sup> See: <a href="https://inclusioninstitute.fpg.unc.edu/sites/inclusioninstitute.fpg.unc.edu/files/handouts/early-relational-health-strategicbrief-2020.pdf">https://inclusioninstitute.fpg.unc.edu/sites/inclusioninstitute.fpg.unc.edu/files/handouts/early-relational-health-strategicbrief-2020.pdf</a>



content, they eat well, then one sees that they are well, they get along with others and they're sociable.]

"Me doy cuenta porque come muy bien, le gusta bailar, es muy activa, le gusta salir a caminar, y cuando regresa ya llega contenta. Cuando no se siente bien, se le nota, a veces llora mucho o cuando no duerme bien, llora mucho y me busca mucho también. Me doy cuenta cuando está sana porque es muy activa

y contenta. Le gusta jugar con sus hermanos." [I can tell because she eats very well, she likes to dance, she's very active, she likes to go out for a walk, and when she comes back she's content. When she doesn't feel well, it's obvious, sometimes she cries a lot, or when she doesn't sleep well she cries a lot and seeks me out a lot too. I know when she is healthy because she is very active and content. She likes to play with her siblings.]

### **Latina Mothers Describe Strong Parent-Child Relationships**

### Close & Safe Relationships Between Parent and Baby

Latina mothers described how their babies have a strong attachment to each of them, sharing that their babies recognize and feel protected by them.

"Con la mirada, siento que [los bebés] distinguen a las personas y cuando escucha mi voz. Mi bebé sabe cuándo yo estoy aquí, ella sabe que soy su mamá, me mira, me reconoce y sabe que todo va a estar bien." [I feel that they can tell people apart by looking at them, and when they hear my voice. My baby knows when I am here, she knows that I am her mama, she looks at me and recognizes me and she knows everything is going to be okay.]

These mothers talked about the importance of breastfeeding, spending time with their babies, and singing and talking as helping to create these early attachments. Breastfeeding was seen as integral to forming strong early relationships with babies.

"La conexión que tiene mi bebé es con mi pecho, desde que uno le da pecho ellos empiezan a reconocerte; ahorita que mi niña tiene año y medio la dejo si tengo una cita con mi madrina y pregunta por mí: 'mamá mamá', y ya cuando yo llego ya está más tranquila, la bebé va por mí, cuando me ve y llego se calma, cuando no estoy pregunta y me busca a mí. Se conecta más uno con los bebés cuando le doy pecho es una conexión muy bonita." [The connection that my baby has is with my breast. Once you nurse them they begin to recognize you. Right now my girl is a year and a half old.

If I have an appointment, I leave her with my godmother and she asks for me: "mama, mama," and then when I come back she is more calm. The baby comes to me, when she sees me and I come she calms down. When I am not there she asks for me and looks for me. One connects more with babies when I nurse them, it is a very beautiful connection.]

"Yo adoro a mis hijos y siempre trato de complacerlos. Si puedo, trato de estar siempre con ellos y enseñarles lo que está bien y lo que está mal." [I adore my children and always try to please them. If I can, well, I try to always be with them and to teach them what's good and what's bad.]

"Cuando era chiquita yo le cantaba, cuando le canto, le hablo, me reconoce." [When she was little I would sing to her - when I sing to her, talk to her, she recognizes me.]

### **Important Parenting Practices**

Latinx mothers identified a number of the important behaviors, practices, and beliefs that they see as indicating close parent-child relationships and good parenting.

#### Showing love, affection, and caring

Latina mothers indicated that they can tell when someone has a very close relationship with their baby, when they see them giving love, affection, and treating their baby well.

"La manera de cómo los papás tratan a sus hijos, uno se da cuenta de cómo son con ellos. Tal vez el cariño que se les dé muestra si



realmente quieren a los niños." [From the way parents treat their children, one can tell how they are with them. Perhaps the affection that they give them shows whether they really love the children.]

#### Setting limits and teaching their values to children

These mothers talked about their role in providing limits and boundaris for children, and the importance of parents as role models:

"Pienso también de cómo poner límites a los niños, porque a veces veo que estos niños están haciendo cosas incorrectas que no deben hacer y los papás no le están prestando atención y que no les importa lo que está haciendo el niño, si está bien o está mal.

También poner límites a lo que está bien y lo que está mal." [I also think about how to set limits for the children, because sometimes I see that these children are doing incorrect things that they shouldn't be doing, and the parents aren't paying attention to them and they don't care what the child is doing, if it's good or bad. Also setting limits about what is good and what is bad.]

"Pues enseñarles valores a nuestros hijos. Antes de estar casada, era más grosera pero cuando ya empecé a tener a mis hijos cambié. Yo quiero que mis hijos sean unos niños buenos, bien portados y respetuosos, pues tengo que darles un buen ejemplo. ¡Mis hijos no dicen malas palabras, gracias a Dios! Trato de no decirles a ellos malas palabras para que no me digan: por qué usted me dice que yo no diga si usted lo está diciendo; no darles mal ejemplo." [Well, teaching values to our children. Before I was married, I was more rude, but when I started to have my children, I changed. I want my children to be good kids, well-behaved and respectful, so I have to set a good example for them. My children don't say bad words, thank God! I try not to say bad words to them so they don't say them to me, why are you telling me not to say something that you are saying...don't set a bad example for them.]

#### Allowing children freedom to explore

A few mothers also mentioned that letting their child be independent and giving them enough space to explore, is an act of parental love.

"A veces nosotros pensamos 'como amo tanto a mi hijo... lo voy a poner en esta burbuja', pero a veces los estamos protegiendo tanto y cuidando tanto, que pensamos que los amamos por protegerlos, pero no les estamos dejando ser libres... como gueremos tener el control; entonces dejarlos explorar un poquito también es amar a los niños." [Sometimes we think that 'since I love my kid so much, I am going to put him in this bubble,' but sometimes we are protecting them and taking care of them so much, that we think that we love them by protecting them, but we aren't letting them be free, since we want to have the control, so letting them explore a little is also loving children.]

#### Tending to baby's physical and emotional needs

Participants also described a variety of ways that parents take care of their children, including tending to their children's' health, nutritional and educational needs. This was also seen as an indicator that a parent wants the best for their children.

"Y por más besitos que les demos, pues también tiene que ver mucho la nutrición y todo eso, es una combinación y un conjunto de cosas que a veces no se puede ver a simple vista si alguien es buen papá o no. También el levantar a los niños a tiempo para ir a la escuela o no llegar tan tarde... Nada más prestarles atención. Yo a veces voy a citas con el doctor y veo que la mamá está en el celular durante todo el tiempo y los niños de ahí brincoteando por todos lados y pidiendo atención. Entonces esa es otra manera de cuidarlos o no cuidarlos." [And the more kisses we give them, well, nutrition and all that has a lot to do with it too, it's a combination and a group of things so that sometimes one can't see just by looking if someone is a good parent or not. Also getting the children up in time to go to school, or not arriving too late... Just pay attention to them. I sometimes go to doctor's appointments and I see that the mother is on



her phone the whole time and the children are there jumping all over the place and asking for attention. So that is another way of taking care of them or not taking care of them.]

Another mother shared that she sees parent-child relationships reflected in the child's behavior.

"Yo diría que también tienen mucho que ver en algunas ocasiones el comportamiento de los niños. Me ha tocado en ocasiones mirar a niños actuar como temerosos. Y una cosa es respeto y otra cosa es temor. Y yo creo que ahí es donde también en el comportamiento de los niños y cuando ellos escuchan el tono de voz de los padres, ahí uno se da cuenta si los papás son amorosos o son fuertes con ellos." [I would say also that sometimes the behavior of the children has a lot to do with it. I've had occasion to see children acting as if they were scared. And respect is one thing, but fear is another. And I believe that that's also where, in the children's behaviors and when they hear their parents' tone of voice, from that one can tell if the parents are loving or if they are strict with them.]

### Parental Support for Children's Growth & Development

Mothers shared the many ways that they support their babies' development and growth. These efforts include providing a daily routine and naps, exposure to different foods for well-rounded nutrition, and talking with baby to stimulate language development.

### The importance of daily routines, physical development and naps

"Hacer ejercicios con ella en las mañanas es parte de la rutina, también es para que ella sepa qué va a pasar; hacerle ejercicios, ponerla bocabajo, darle masajes en la espalda y moverle los piecitos." [Doing exercises with her in the mornings is part of the routine, also so that she knows what's going to happen, doing exercises with her, putting her on her tummy, giving her back massages and moving her little feet.]

"Mi niña iba a la escuela y trato de seguir la misma rutina de la escuela (en la casa) para darle un balance para que cuando regrese a la escuela todo esté bien con su rutina." [My girl was going to school and I try to follow the same routine as the school to give her balance so that when she returns to school everything will be okay with her routine.]

"Yo me aseguro de que al menos tomen una siesta, por lo menos una hora durante al día porque si no están hiperactivos." [I make sure that they take at least one nap, for at least one hour during the day, because if not, they are hyperactive.]

While routine is important, one mother also stressed the **importance of not overprotecting children** and "letting them be."

"... me gusta dejarlos ser, no me gusta presionarlos para nada. Él empezó a caminar y gatear al tiempo que él quiso. Al mayor quizás si lo forcé, estaba yo muy joven y escuchaba todo lo que los demás me decían y lo sobreprotegí mucho. A los demás ya no me preocupe mucho, los estamos haciendo dejar ser, que explore las cosas; si se cae... se cayó, lo he dejado ser, a ser más libre, que a su tiempo haga lo que él quiera. Si se cayó, lo miro y si se cae, que se de cuenta que se cayó." [... I like to let them be, I don't like to pressure them for anything. He started to walk or crawl when he wanted to. The older one I might have forced, I was very young and I listened to what everyone else told me and I overprotected him a lot. For the rest I didn't worry as much, we were letting them be, so they would explore things, if they fell they fell, I have let him be, to be more free and do what he wanted in his own time. If he falls I look at him and if he falls he should realize that he fell.]

#### Exposure to different foods

Good nutrition and exposure to wide variety of foods and flavors were also featured in their responses.

"Algo que estoy haciendo con mi nena es introducir diferentes comidas, muchos sabores, muchos vegetales para que coma de todo en el futuro." [One thing I am doing with my little girl is introducing her to different



### foods, many flavors, many vegetables so that she will eat everything in the future.]

#### Promoting language development

Parents also shared that they found any reason to talk to their baby to promote language development.

"Algo que hacía antes, cuando los llevaba a la tienda, pasábamos por el área de las frutas y verduras, les decía: 'ay mira allá hay una zanahoria'! 'Y para que es?' Esperaba que me dijeran la respuesta y cuando cocino también los motivó a hablar y expandir el lenguaje." [Something I did before, when I would take them to the store, we would go through the produce section and I would say to them: "Look, there's a carrot!" "What is it for?" I would wait for them to tell me the answer, and when I cook I also encourage them to talk and expand their language.]

### Parents Take Pride in Their Children's Accomplishments

The Latina mothers had many stories about when their babies made them proud. These stories included their children's achievements in physical development, speech and language development, social development, and toilet training.

"Ahorita el más pequeñito [de mis hijos] lo que me da mucho orgullo es que él no se muere de hambre, él va al refrigerador agarra la cuchara para el yogurt, el tenedor; [sabe que es] para otra cosa, el ya sabe para qué sirven las cosas, el agarra lo que necesita. Me dice mamá "ah" que quiere comer y me da orgullo que sepa para qué sirve la cuchara y el tenedor, me dice cuando quiere comer." [Right now, the little one, what makes me really proud is that he won't die of hunger, he goes to the refrigerator, gets a spoon for the yogurt, the fork for something else, he already knows what things are for, he grabs what he needs. He says to me "mama" and "ah," that he wants to eat, and it makes me proud that he knows what the spoon and fork are for and he tells me when he wants to eat.]

### **Early Parenting Challenges for Latina Mothers**

Latina mothers described in detail the biggest challenges they went through with their babies. Many shared various problems that they experienced with their babies and how it impacted the whole family. They highlighted sleeping schedule issues, teething, breastfeeding, car driving and complications related to premature birth.

"Lo que me tocó pasar fue bien duro, porque cuando nació mi niño no podía dormir, su horario de dormir era completamente diferente, así tardamos ocho meses. [EI] dormía en las tardes y despertaba en las noches y ya no dormía. Yo trabajaba y nos turnábamos con mi esposo. La doctora nos ayudó, me decía muevan la cuna acá, saquen la cuna allá, que hagan esto y el otro, hicimos todo lo posible y no se acostumbraba a dormir; hasta que llegó el mes 8... y pudimos dormir. Fue un reto que vivimos mi esposo, yo y mis niños también, porque ellos también padecían todo eso...Fue super difícil." [What I had to go through was really hard, because when my boy was born he couldn't sleep, his sleep schedule was completely different. We went on eight months like that. He would sleep in the afternoons and wake up at night and not sleep any more. I was working and taking turns with my husband. The doctor helped us, she told me to move the cradle here, take the cradle out there, do this, that, and the other thing, we did everything possible and he wouldn't get used to sleeping; until he got to month eight and suddenly we slept. It was a challenge that we lived through, me and my husband and my children as well, because they also suffered through all of that...It was super hard.]

"Yo también he tenido un reto difícil con mi niña porque a los seis meses le comenzaron a salir los dientes, pero los dos de arriba y los dos de abajo. Y yo sufrí mucho con ella, porque le daba mucha fiebre y alta. Fue muy pesado, porque le estaban saliendo cuatro dientes a la vez, y fue muy feo la fiebre que le dio...Ella



sufrió mucho con los dientes y yo también." [I also have had a difficult challenge with my girl because at 6 months her teeth started to come in, and it was two on the top and two on the bottom. And I suffered a lot with her, because it gave her a lot of high fevers. It was very intense, because she had four teeth coming in at once, and the fever it gave her was horrible...She suffered a lot with her teeth, and I did too.]

More than one mother explained how hard it was for her to leave her premature baby in the hospital.

"El desafío más grande que he tenido entre todos mis embarazos y mis hijos ha sido el tenerme que venir del hospital y tenerla que dejar a ella [su bebe] ahí. Y estar constantemente yendo al hospital todos los días a verla y tenerme que separar de ella, eso fue lo más horrible que tuve que pasar con ella y con todos mis hijos, pero especialmente con ella, y más porque tuvo que estar mucho más tiempo en el hospital que los otros niños." [The biggest challenge that I have had with all of my pregnancies and my children has been having to leave the hospital and having to leave her there. And being constantly going to the hospital every day and having to separate myself from her, that was the most horrible thing I had to go through with her and all of my children, but especially with her, and more because she had to be in the hospital much longer than the other children.]

Another mother shared how difficult breastfeeding was when her baby had gotten used to drinking milk from a bottle.

"Yo sí creo que uno de los retos con mi último hijo fueron varios, pero uno fue de que a los cinco días de haberlo tenido me hicieron cirugía del cerebro, entonces, por todo el medicamento y la radiación que estuve, no le puede darle pecho directamente, pero como yo quería darle pecho; entonces cada dos horas me sacaba la leche y no le podía dar esa leche por todo el medicamento que tomaba, entonces tenía que tirarla... Ya cuando yo le quise dar el pecho, que fue a los 4 meses,

cuando terminé la radiación, no me quiso recibir el pecho. Ya estaba acostumbrada con la mamila, no quiso agarrar el pecho y eran gritos y gritos...y yo ya estaba cansada de estar sacándome la leche con la máquina...el rehusaban el pecho, me lo tiraba hasta que al fin lo agarró..." [I do believe that one of the challenges with my last boy, there were several, but one was that five days after the birth I had brain surgery, and then, because of all of the medication and the radiation that I had, I couldn't nurse him directly, but because I wanted to nurse him, every two hours I pumped my milk, and I couldn't give him that milk because of all the medication I was taking, so I had to dump it. Meanwhile, they were giving us, from the milk bank, they were giving us milk. And then when I wanted to nurse him, at four months when the radiation was done, he didn't want to take the breast. He was already accustomed to the bottle nipple, he didn't want to take the breast, and there were screams and screams... and I was tired at that point of pumping with the machine...he refused the breast, he pushed it away, until finally he took it...]

### Who Do You Go to for Support?

Latina mothers expressed that they would have liked to meet and get support from other families who have gone through the same obstacles with their children.

"Yo creo que sí me hubiera ayudado más conocer a una mamá que estuviera pasando por lo mismo que yo, que me hubiese aconsejado que hacer o qué pasos se venían. Yo creo que eso si me hubiera ayudado un poquito más, para no confundirme con tanta información que me dieron y al final de cuentas, no fue nada de lo que me estaban diciendo que podía hacer. Entonces... tal vez platicar y desahogarme con alguna mamá que estaba pasando por lo mismo." [I believe that it would have helped me more to know a mother who was going through the same thing as me, who could have advised me on what to do, or what steps were coming. I believe that would have helped me a bit more, so that I



didn't confuse myself with all the information they gave me, and in the end, it wasn't any of the things that they were telling me it could be. So, I believe that yes, maybe talking with and unburdening myself with a mother who was going through the same thing.]

### The Role of Medical Providers in Supporting Early Relationships

Fewer than half of the mothers reported that they reached out to their medical providers to address concerns beyond the babies' physical health. Some mothers reported instances where they were able to get support beyond physical concerns, with these examples related in particular to children with special needs or challenges.

"Yo tuve una conversación con mi doctor sobre mi niña, porque como ella estuvo mucho tiempo en la incubadora, no pudimos hacer el mismo "bond" que cuando estás con tu niño en el mismo cuarto y lo puedes tocar. Con ella tuve que trabajar un poco más, para que me aceptara o para comunicarse con otros niños o que dejara que las demás personas la miraran, la tocaran... No quería que nadie la tocara, entonces yo sí tuve que hablar con mi doctor sobre eso y tuvimos que ir poquito a poquito, especialmente en la escuela, a que dejara que las maestras la tocaran, que los otros niños pudieran jugar con ella; porque era de las que no dejaban que nadie la tocara, como que si fuera una muñeca de porcelana, que no me toquen,... entonces yo tuve que trabajar mucho sobre eso con el doctor de ella." [I had a conversation with my doctor about my girl, because she was in an incubator for a long time. We couldn't form the same bond that you can when you are with your child in the same room and you can touch them. With her I had to work a little more so that she would accept me or so that she would communicate with the other children, or so that she would

let other people look at her or touch her... She didn't want anyone to touch her, so I had to talk with my doctor about that and we had to go little by little, especially at school, so that she would let the teachers touch her, so that the other children could play with her, because she was one of those kids who wouldn't let anyone touch her, as if she were a porcelain doll, don't let them touch me, so I had to work on that a lot with her doctor.]

One mother shared how her doctor was supportive when she was struggling with an uncertain diagnosis for her older child who was exhibiting symptoms of autism and hyperactivity.

"...le agradezco al doctor me tuvo tanta paciencia; le puedo dar a mi hijo esos exámenes. En un lapso de seis meses le hizo un examen, especialmente para los que él ocupaba y si hizo un examen donde lo relajaron mucho... Tuve que conectar al doctor, para que hablara con la maestra, nos juntamos para hacer un plan, especialmente para mi hijo, hasta ahorita mi hijo tiene un plan en la escuela." [I appreciate that the doctor was so patient with me, I could give those tests to my son. After six months they did a test on him, especially for those [behaviors] that he was doing, and they did a test where they relaxed him a lot...I had to connect with the doctor, so that he would talk with the teacher. We met to make a plan especially for my son, and my son still has a plan at the school.]

### **Experiences with Medical Providers**

Most of the Latina mothers described good interactions with their medical providers. They shared that they value having close relationships with their children's doctors, and that they want to be heard. While it is not always easy to establish a close relationship, it is very important to them.

### Close Relationships are Paramount for Latinx Families

Positive examples of experiences with medical providers included interactions with doctors who get



to their know patients, speak their language and spend the necessary time without rushing, and with this they are able to better meet their needs due to the relationship they've built.

"Tengo el mismo pediatra para ambas [niñas] y las conoce a las dos muy bien... y casi siempre llevo a ambas [al doctor]; entonces se acuerda muy bien del nombre de ellas, de lo que les gusta y me pregunta cómo sigue [nombre de la niña]? ¿Está usando sus lentes? Ya veo que si ya los tiene, ¿cómo está tu esposo? ¿Cómo está el trabajo? ¿A ti cómo te va? ¿Qué has hecho? ¿Sigues en el mismo trabajo? Se acuerda absolutamente de todos los detalles...en cuestión de la relación eso lo aprecio mucho, aparte el pediatra habla español y ella ya sabe que hablo español, no le tengo que decir que me tiene que dar información en ambos idiomas, porque a mi esposo le gusta leer mayormente en español, eso aprecio mucho que sepa de nuestras necesidades y que se preocupe y pregunte no solamente por la salud de las niñas, pero también de mí. [El doctor me pregunta] ¿Y tú cómo estás? Asegúrate de que si estás teniendo esos síntomas de depresión posparto, que hables con tu médico. Yo lo aprecio muchísimo." [I have the same pediatrician for both [children], and she knows them both very well...and I almost always take both of them [to the doctor]; then she remembers both of their names very well, what they like, and asks me 'How's it going [daughter's name]? Are you using your glasses? I see that you have them, how is your husband? How is work? How is it going for you? What have you done? Are you in the same job?' She remembers absolutely all the details... with regards to the relationship, that I appreciate a lot, and the pediatrician speaks Spanish and he knows that I speak Spanish, I don't have to tell him that he has to give me information in both languages, because my husband prefers to read mostly in Spanish, I really appreciate that he knows our needs and that he is concerned and asks about not only the girls' health but also about me. And you, how are you? Be sure that if you are having

any of those postpartum depression symptoms, that you talk with your doctor. I appreciate it a lot.]

"[la doctora] me hace sentir súper cómoda siempre, se toma el tiempo, habla con los niños, les pregunta cómo están, cómo ha crecido, y cómo les van en la escuela...se toma tiempo de hablar con mis hijos...me gusta mucho que la doctora se tome el tiempo de preguntarles a ellos y si no pueden contestar las preguntas entonces voltea conmigo, y dice a ver ¿qué pasó?." [the doctor] always does make me feel super comfortable, she takes the time, talks with the children... asks them 'how they are, how they've grown,' and 'how school is going for them?' She takes the time to talk with my children. I like that a lot, that the doctor takes the time to ask them and if they can't answer the questions then she turns to me, and says 'Let's see what happened?']

One mother shared a story about how she felt supported by her medical provider after the child's teacher recommended that their child take medication to make him less active.

"Una de las maestras me dijo: ' lleva a tu niño al doctor para que le den medicamento, porque es muy activo'. ¿Entonces le dije por qué medicamento? Es porque tu niño es demasiado activo y aquí todos los niños se le quedan viendo y no quieren trabajar. Le dije entonces si le molesta, maestra; puedo hablar de que mejor tome clases en mi casa, porque yo no le voy a dar medicina a mi hijo para que se calme o se duerma o se tranquilice.

Entonces tuve que hablar con la pediatra y me dijo que está muy mal. Yo no recomiendo medicina. No te voy a dar medicina para tu hijo y menos si no sabemos qué diagnóstico de tu hijo. No te puedo recomendar algo hasta que lo chequeen bien. Entonces, yo hablé con el director y le dije lo que me había dicho la maestra y la maestra después se disculpó y me dijo que ella tenía un hijo que se parece al mío." [One of the teachers said to me: 'Take your boy to the doctor so that they can give him medication, because he is very active.' So, I said to her, why medication? It's



because your boy is too active and here all the children end up watching him and they don't want to work. Then I told her that if he bothers you, teacher, I can talk about it maybe being better for him to take classes at home, because I am not going to give medicine to my son so that he calms down or goes to sleep or is tranquil. Then I had to talk with the pediatrician and he said it's very bad. I don't recommend medication. 'I am not going to give you medication for your son, and even less if we don't know your son's diagnosis. I can't recommend anything until we examine him thoroughly.' Then, I talked with the director and I told him what the teacher had said, and later the teacher apologized and told me that she has a son who seems like mine.]

## The Relationship Suffers When Medical Providers Don't Spend Appropriate Time and are Dismissive of Concerns

When providers rush families, have not taken the time to address the families' concerns appropriately or deny them, and are negligent the relationship suffers and the parents are displeased and frustrated.

"Con mi primer niño, que ya tiene 12 años, iba con una pediatra y nos cambiamos de lugar... el servicio era muy rápido; ¿el paciente que sigue? es que tenía otra pregunta, 'oh, lo siento, a la otra cita cuando vengas a las vacunas'. Me tuve que salir de ahí, no me sentí a gusto" [With my first boy, who is 12 now, I also went to one pediatrician and we changed locations... and I had to go to the other office and I felt the same, like the service was very fast, the next patient?, 'it's just that I have another question,' 'oh, I'm sorry, at the next appointment when you come for the vaccinations.' I had to leave there, I didn't like it.]

This was especially pronounced for Latina mothers of children with special needs. They shared many stories about medical providers who downplayed/ignored the mother's concerns, could not identify the

**problem**, and **didn't refer them to specialists** early enough for the appropriate early intervention.

"El doctor no sabía cómo ayudarme, pienso que me hubiera mejor referido a alguien más, porque es algo que le pregunté, tú crees que debo buscar ayuda diferente o buscar algún otro médico o un especialista que me ayude porque él niño no hablaba para nada y él [doctor] me decía: 'No está bien, solamente es cuestión de tiempo. ¡Todo está bien! ¡No te preocupes! todos los niños son diferentes!'. Yo soy mamá de cinco hijos, él es mi cuarto hijo, y sabía que algo no estaba bien, entonces yo creo que él [doctor] hubiera sido un poco más abierto, me hubiera dicho; sabes que no sé cómo lidiar con esto. Te voy a referir a otra persona." [The doctor didn't know how to help me, I think it would have been better if he had referred me to someone else, because it's something that I asked him about, 'do you think I should seek out different help or look for another doctor or a specialist who can help me,' because the boy wasn't speaking at all, and he told me, 'No, it's fine, it's just a question of time. Everything is fine. Don't worry, all children are different.' I am the mother of five children, he is my fourth child, and I knew that something wasn't right, so I believe that he could have been a little more open, he could have said to me, 'you know what, I don't know how to deal with this. I am going to refer you to someone else.""]

"En mi caso, se me dificultó encontrar ayuda especial. Su pediatra; no quiero ofenderlo ni sonar grosera, pero es una persona mayor y él me decía, 'que era normal y que era normal y que era normal,' pero tú sabes cuando algo es diferente a tus otros hijos. Yo tardé mucho en encontrar la ayuda correcta. Aún ellos, algunos especialistas que lo ha visto, no se han decidido si tiene autismo o no." [In my case, it was difficult for me to find special help. His pediatrician, I don't want to offend him or sound rude, but he is an older person and he was saying 'it's normal, it's normal, it's normal,' but you know when something is different from your other children. It took me



a long time to find the right help. Even they, some specialists I have seen, haven't decided if he has autism or not.]

### **Areas of Opportunity for Medical Providers**

In order for medical providers to support Latinx families with small babies, they need to **tend to the relationship**, which is easier when the provider **shares the families cultural and linguistic background**.

Spend time to build relationship with Latinx families

"...Me gustaría que al menos tengan el interés de tener una relación con nosotros, no andar a las carreras como solamente entrada por salida." [...I would at least like to see that they are interested in having a relationship with us, not walking the halls, just popping in and out.]

Need Hispanic/Latinx and Culturally-Competent Providers

Latina mothers also expressed a preference for having when providers who share their ethnic and linguistic background. Having more Hispanic/Latinx and culturally responsive and competent providers could improve the likelihood that providers can effectively and authentically build relationships with Latinx families.

"...Que hubiera doctores que pudieran hablar mi idioma, hay algunas palabras que en inglés no las sé decir o entender, entonces para mí sería algo que yo me pudiera comunicar mucho mejor con los doctores en mi lenguaje" [...If there had been doctors who could speak my language - there are some words that I don't know how to say or understand in English, so for me it would be something that would help me be able to communicate much better with the doctors in my language.]

Medical providers need training to be able to identify and treat children with special needs.

"...[los doctores] te dicen puede ser el autismo o puede ser hiperactividad, o puede ser esto, entonces estuve de oficina en oficina, con diferentes doctores. Y así eran las citas cada 15 días o cada semana... y al final se dieron cuenta que es simplemente emocional lo que él tiene...Lo más importante de todo es que no fue nada de lo que los doctores...me dijieron" [...[the doctors] say to you 'it could be autism or it could be hyperactivity, or it could be this.' So I was going from office to office to see different doctors. So there were appointments every 15 days or every week... at the end they realized that what he has is simply emotional...the most important of all was that it wasn't any of the things that the doctors...had told me.]

As described above, families had many stories of frustration and delayed access to services due to their perception that the medical provider was unable to diagnose their child and unwilling to refer them to specialists or doing it at the appropriate time. Families caring for special needs children need extra support and care during the diagnosis process. Mothers shared that it would be helpful if efforts were made to streamline the process to ensure appropriate treatment and services are made available in a timely manner.

### **Summary & Takeaways**

One of the most important takeaways from this group of Latinx mothers is that they clearly understood and described the importance of foundational early relationships with their children, and see relationships with family members, informal friends/networks, and health care providers as a source of well-being. In particular, these mothers described:

 Strong connections with their infants that are intentionally created through loving, affectionate parenting. These connections were seen as essential to the well-being of the mothers as well as the babies.



- Stress and distress are experienced when there are challenges in creating these connections (e.g., when infants are hospitalized, premature, or have other early health or social-emotional challenges).
- Overall, these mothers held a holistic view of their child's wellness, one that includes nurturing physical health, language, independence, and social emotional health through their role as parents;

Many of these mothers see health care professionals as an important source of information and support for themselves and their children, and expressed a willingness to go to these providers despite some of the challenges they had encountered. These challenges happened when Latinx mothers experienced medical providers as not listening, rushing, and not "tending to the relationship".

Tending these relationships with mothers and families was seen as foundational for building trust between these mothers and their health care providers. To this end, these mothers recommended:

- Creating systems changes that would allow providers to spend more time with families during health care visits;
- Having access to more culturally-specific health care providers, who not only speak Spanish, but understand the Latinx culture and values;
- Respecting and honoring parents' roles as having expertise in understanding their children, and in particular, responding to mothers' concerns about developmental delays and simplifying systems for accessing developmentally supportive systems.



### **Appendix A**

#### **Focus Group Questions**

- 1. First, let's talk about what it means to you to have a positive, caring relationship with your baby.
  - a. What do you do to support your baby's development and take care of your baby?
  - b. What does it mean to have a close, secure, relationship or connection with your baby?
  - c. What do you see in other people with their infants that lets you know that person loves and strives for the best future for their baby?
  - d. What do you think it means for a baby to be "emotionally and socially healthy"? What does this look like to you? Why does it matter?
- 2. What helps parents have positive, caring relationships with their babies? What do parents need to have for this to happen?
  - a. Where do you get support or resources to help you as a parent?
- 3. Other than questions about health, have you ever talked with a doctor or nurse about what's going well or what is challenging about taking care of your baby?
  - a. If so, what has this been like? Was it helpful?
  - b. Has there ever been a time when you, or others in your family or community have had a negative experience with a health care provider, especially regarding your parenting or the way you provide care to you baby? What happened, tell me about this? What would have made this go better?
- 4. What do you think health care providers should know about how you, your family, or others in your community in order to better support parents and their babies?
  - a. What would make visits with your doctor or nurse feel more supportive?
- 5. Is there anything else you think that we need to know about these early relationships, your experiences, what helps other parents and babies have good relationships and how health care providers can help?

